CABINET FOR HEALTH AND FAMILY SERVICES

Department for Public Health

Division of Maternal and Child Health

(Amendment)

911 KAR 2:120. Kentucky Early Intervention Program evaluation and eligibility.

RELATES TO: KRS 200.654, 34 C.F.R. 303.11, 303.300, 303.322, 20 U.S.C. 1471 to 1476

STATUTORY AUTHORITY: KRS 194A.030(7), 194A.050, 200.660(7), 200.650-676, 34 C.F.R. 303.322, 20 U.S.C. 1474, 1475 (a)(10), EO 2004-726

NECESSITY, FUNCTION AND CONFORMITY:

KRS 250.660 requires the Cabinet for Health and Family Services to administer all funds appropriated to implement provisions of KRS 200.650 to 200.676, to enter into contracts with services providers, and to promulgate administrative regulations. This administrative regulation establishes the evaluation and eligibility requirements for First Steps, Kentucky's Early Intervention Program.

Section 1. Evaluation

(1) A child referred to the First Steps Program shall be initially evaluated to determine eligibility if:

(a) They are suspected of having a developmental delay as confirmed by the cabinet approved screening protocol; and

(b) The child does not have an established risk condition.

(2) A child with an established risk shall have a five (5) area assessment done by a primary level evaluator using a cabinet-approved criterion referenced assessment instrument in lieu of a primary level evaluation. If a child is eligible due to an established risk condition of hearing loss, the five (5) area assessment shall be performed by a speech therapist or a teacher of the deaf and hard of hearing who is approved as a primary level evaluator.

(3) A determination of initial eligibility pursuant to Section 2 of this administrative regulation, assessments in the identified area of delay if needed and in accordance with 911 KAR 2:130, and the initial IFSP team meeting shall occur within forty-five (45) calendar days after a point of entry receives an initial referral.

(a) If a determination of initial eligibility, assessments, and initial IFSP team meeting does not occur within forty-five (45) calendar days, the circumstances contributing to the delay in meeting shall be documented.

(b) If a family is referred for a determination of initial eligibility and the family is under court order or a social services directive to enroll the child in First Steps, the court or social service agency shall be informed within three (3) working days by the Point of Entry staff if the family refuses the determination of eligibility.

(4) Child records of evaluations transferred from a developmental evaluator outside the Kentucky First Steps System shall be reviewed by the Point of Entry staff and shall be utilized for eligibility determination if:

(a) The records meet First Steps evaluation time lines established in subsection (5) (a) of this section; and

(b) The records contain the developmental evaluation information established in subsection (12) (a) and (b) of this section.

(5) The primary level evaluation shall be utilized to determine eligibility of children without an established risk, determine developmental status, establish the baseline for progress monitoring, and make recommendation for the Individual Family Service Plan (IFSP) outcomes.

(a) If there is a recent medical or developmental evaluation available, as described in subsections (c) and (d) of this section, it shall be used to determine eligibility if:

1.a. For children under twelve (12) months of age, the evaluation was performed within three (3) months prior to referral to First Steps; or

b. For children twelve (12) months to three (3) years of age, the evaluation was performed within six (6) months prior to referral to First Steps;

(b) Primary level evaluation shall provide evaluation in the five (5) developmental areas identified in Section 2(1)(c)1 through 5 of this administrative regulation using norm-referenced standardized instruments that provide a standard deviation score in the total domain for the five (5) areas and a cabinet approved criterion assessment.

(c) The primary level evaluation shall be provided by:

1. A physician or nurse practitioner; and

2. A primary evaluator approved by the cabinet.

(d) A primary level evaluation shall include:

1. A medical component completed by a physician or nurse practitioner that shall include a:

a. History and physical examination;

b. Hearing and vision screening; and

c. Recent medical evaluation that shall be in accordance with the timelines established in subsection 5(a)1a and b of this Section; and

2. A developmental component completed by a cabinet-approved primary level evaluator that shall include:

a. A review of pertinent health and medical information and a recommendation of a determination of eligibility;

b. Completion of appropriate instrument(s) to determine the child's unique strengths and needs;

c. A statement of eligibility;

d. Results which shall be interpreted to the family.

(6) If the child does not have an established risk condition and is determined not eligible, the POE staff shall discuss available community resources, such as Medicaid, EPSDT, the Department for Public Health's and the Commission for Children with Special Health Care Need's (CCSHCN's) Title V programs, and other third-party payors.

(7) At the initial IFSP meeting, the IFSP team shall:

(a) Include the following members at a minimum:

1. The parent or guardian of the child;

2. Other family members as requested by the parent or guardian;

3. An advocate or person outside of the family, if the family requests that the person participate;

4. The service coordinator;

5. The evaluator who performed an assessment on the child; and

6. As appropriate, persons who will be providing services to the child or family;

(b) Verify the child's eligibility;

(c) Review the evaluation and assessment information;

(d) Review the family routines, priorities, and concerns;

(e) Determine the family's desired outcomes according to the child's strengths and the family's routines, priorities, and concerns; and

(f) Determine the services necessary to meet the unique needs of the child and family in order to achieve the outcomes identified.

(8) Redetermination of eligibility shall occur at least annually, shall be part of the ongoing assessment and shall include an assessment in all five (5) areas by the Primary Service Provider (PSP) using a Cabinet-approved criterion referenced instrument. If person or persons directly involved in conducting the evaluation and assessments are unable to attend an IFSP meeting, arrangements must be made for their involvement by other means including participating in a telephone conference call, having a representative attend the meeting, or making pertinent records available at the meeting.

(9) A child without an established risk condition shall have continuing eligibility if the child meets the criteria set forth in 911 KAR 2:120 Section 2(4)(a) and (b).

(a) Redeterminations of eligibility shall not be used to address concerns that are medical in nature.

(b) Based on the result of the redetermination of eligibility, the IFSP team shall:

1. Continue with the same outcomes and services;

2. Continue with modified outcomes and services; or

3. Transition the child from First Steps services.

(10) An annual IFSP meeting shall be held in accordance with KRS 200.664(7), to determine continuing program eligibility and the effectiveness of services provided to the child.

(11) A review of the child's First Steps record by the Record Review Team shall be the second level in the First Steps evaluation system that shall be utilized to determine eligibility, medical or mental diagnosis, program planning, or plan evaluation.

(a) Upon obtaining a written consent by the parent or guardian, a service coordinator shall submit a child's record to the Department for Public Health or the designee for a record review if:

1. A child does not meet eligibility guidelines at the primary level, but the primary level evaluator and the family still have concerns that the child is developing atypically and a determination of eligibility based on professional judgment is needed; or

2. The IFSP team requests an intensive level evaluation for the purposes of obtaining a medical diagnosis or to make specific recommendations where the medical condition would require the early intervention services to be modified for the individual child.

(b) Upon receiving a referral, a Record Review Team shall conduct a record review and issue findings within ten (10) calendar days of receipt of the request.

(c) Intensive level evaluations shall be conducted by a team of professionals as determined by the Department for Public Health.

1. A board certified medical professional with expertise in early childhood development as listed below:

a. A board certified developmental pediatrician;

b. A pediatrician who has experience in the area of early childhood development;

c. A board certified pediatric psychiatrist; or

d. A board certified pediatric neurologist; and

e. One (1) or more developmental professionals identified in 911 KAR 2:150, Section 1.

(12) Family rights shall be respected and procedural safeguards followed in providing evaluation services. Written parental consent shall be obtained before conducting an evaluation or assessment.

(13) An evaluation report shall be written in accordance with the established time frames and shall be written in clear, concise language that is easily understood by the family.

Section 2. Eligibility.

(1) Except as provided in subsection (2) or (3) of this section, a child shall be eligible for First Steps services if he is:

(a) Aged birth through two (2) years;

(b) A resident of Kentucky at the time of referral and while receiving a service;

(c) Through the evaluation process determined to have fallen significantly behind developmental norms in the following skill areas:

1. Total cognitive development;

2. Total communication area through speech and language development, which shall include expressive and receptive;

3. Total physical development including motor development, vision, hearing, and general health status.

4. Total social and emotional development; or

5. Total adaptive skills development; and

(d) Significantly behind in developmental norms as evidenced by the child's score being:

1. Two (2) standard deviations below the mean in one (1) skill area; or

2. At least one and one-half (1 ½) standard deviations below the mean in two (2) skill areas.

(2) If a norm-referenced testing reveals a delay in one (1) of the five (5) skill areas but does not meet the eligibility criteria required by subsection (1)(d) of this section:

(a) A more in-depth standardized test in that area of development may be administered if the following is evident:

1. The primary level evaluator and the family have a concern or suspect that the child's delay may be greater than the testing revealed; and

2. A different norm-referenced test tool may reveal a standardized score which would meet eligibility criteria; and

3. There is one (1) area of development that is of concern.

(b) The results of the alternate testing required by paragraph (a) of this subsection shall determine the child's eligibility if the standardized scores indicate a delay of greater than two (2) standard deviations.

(3) A child shall be eligible for First Steps services if the child:

(a) Is being cared for by a neonatal follow-up program and its staff determine that the child meets the eligibility requirements established in subsection (1) or (4) of this section; or

(b) In accordance with KRS 200.654(10)(b), has an established risk condition diagnosed by a physician and documented in the medical records from the list

in the attached table or as identified in First Steps policy.:

(4) A child shall have continuing program eligibility for First Steps services if the child is under three (3) years old, is a resident of Kentucky, and the result of the most recent semi-annual progress review demonstrates:

(a) Any ongoing delay or failure to attain an expected level of development in one or more developmental areas; and

(b) Consensus of the IFSP team that continued First Steps services are required in order to support continuing similar levels of developmental progress.

(5) Children referred to the First Steps Program born at less than thirty-seven (37) week gestational age shall be assessed using an adjusted gestational age during evaluation and assessment.

(6) When a child who is less than six (6) months corrected age, the primary evaluation shall be done at an approved Intensive Level Clinic and preferably the Neonatal Intensive Care Unit Follow-Up Clinic .

(7) The following is the established risk condition list:

Aase-Smith syndrome
Aase syndrome
Acrocallosal syndrome
Acrodysostosis
Acro-Fronto-Facio-Nasal Dysostosis
Adrenoleukodystrophy
Agenesis of the Corpus Callosum
Agyria
Aicardi syndrome
Alexander's Disease
Alper's syndrome
Amelia
Angelman syndrome
Aniridia

Anophthalmia/Microphthalmia
Antley-Bixler syndrome
Apert syndrome
Arachnoid cyst with neuro-developmental delay
Arhinencephaly
Arthrogryposis
Ataxia
Atelosteogenesis
Autism
Baller-Gerold syndrome
Bannayan-Riley-Ruvalcaba syndrome
Bardet-Biedl syndrome
Bartsocas-Papas syndrome
Beals syndrome(congenital contractural arachnodactyly)
Biotinidase Deficiency
Bixler syndrome
Blackfan-Diamond syndrome
Bobble Head Doll syndrome
Borjeson-Forssman-Lehmann syndrome
Brachial Plexopathy
Brancio-Oto-Renal (BOR) syndrome
Campomelic Dysplasia
Canavan Disease
Carbohydrate Deficient Glycoprotein syndrome
Cardio-Facio-Cutaneous syndrome
Carpenter syndrome
Cataracts - Congenital
Caudal Dysplasia
Cerebro-Costo-Mandibular syndrome
Cerebellar Aplasia/Hypoplasia/Degeneration
Cerebral Atrophy
Cerebral Palsy
Cerebro-oculo-facial-skeletal syndrome
CHARGE Association
Chediak Higashi syndrome
Chondrodysplasia Punctata
Christian syndrome
Chromosome Abnormality a.unbalanced numerical (autosomal) b. numerical trisomy (chromosomes 1-22) c. sex chromosomes XXX; XXXX; XXXXX; XXXY; XXXXY

CNS Aneurysm with Neuro-Developmental Delay
CNS Tumor with Neuro Developmental Delay
Cockayne syndrome
Coffin Lowry syndrome
Coffin Siris sydrome
Cohen syndrome
Cone Dystrophy
Congenital Cytomegalovirus
Congenital Herpes
Congenital Rubella
Congenital Syphilis
Congenital Toxoplasmosis
Cortical Blindness
Costello syndrome
Cri du chat syndrome
Cryptophthalmos
Cutis Laxa
Cytochrome-c Oxidase Deficiency
Dandy Walker syndrome
DeBarsy syndrome
DeBuquois syndrome
Dejerine-Sottas syndrome
DeLange syndrome
DeSanctis-Cacchione syndrome
Diastrophic Dysplasia
DiGeorge syndrome (22q11.2 deletion)
Distal Arthrogryrosis
Donohue syndrome
Down syndrome
Dubowitz syndrome
Dyggve Melchor-Clausen syndrome
Dyssegmental Dysplasia
Dystonia
EEC (Ectrodactyly-ectodermal dysplasia-clefting) syndrome
Encephalocele
Encephalo-Cranio-Cutaneous syndrome
Encephalomalacia
Exencephaly
Facio-Auriculo-Radial dysplasia
Facio-Cardio-Renal (Eastman-Bixler)syndrome
Familial Dysautonomia (Riley-Day syndrome)

Fanconi Anemia
Farber syndrome
Fatty Acid Oxidation Disorder (SCAD, ICAD, LCHAD)
Femoral Hypoplasia
Fetal Alcohol syndrome/Effects
Fetal Dyskinesia
Fetal Hydantoin syndrome
Fetal Valproate syndrome
Fetal Varicella syndrome
FG syndrome
Fibrochondrogenesis
Floating Harbor syndrome
Fragile X syndrome
Fretman-Sheldon (Whistling Facies) syndrome
Fryns syndrome
Fucosidosis
Glaucoma - Congenital
Glutaric Aciduria Type I and II
Glycogen Storage Disease
Goldberg-Shprintzen syndrome
Grebe syndrome
Hallermann-Streiff syndrome
Hays-Wells syndrome
Head Trauma with Neurological Sequelae/Developmental Delay
Hearing Loss (30dB or greater in better ear as determined by ABR audiometry or audiometric behavioral measurements)
Hemimegalencephaly
Hemiplegia/Hemiparesis
Hemorrhage-Intraventricular Grade III, IV
Hereditary Sensory & Autonomic Neuropathy
Hereditary Sensory Motor Neuropathy (Charcot Marie Tooth Disease)
Herrmann syndrome
Heterotopias
Holoprosencephaly (Aprosencephaly)
Holt-Oram syndrome
Homocystinuria
Hunter syndrome (MPSII)
Huntington Disease
Hurler syndrome (MPSI)
Hyalanosis
Hydranencephaly

Hydrocephalus
Hyperpipecolic Acidema
Hypomelanosis of ITO
Hypophosphotasia-Infantile
Hypoxic Ischemic encephalopathy
I-Cell (mucolpidosis II) Disease
Incontinentia Pigmenti
Infantile spasms
Ininencephaly
Isovaleric Acidemia
Jarcho-Levin syndrome
Jervell syndrome
Johanson-Blizzard syndrome
Joubert syndrome
Kabuki syndrome
KBG syndrome
Kenny-Caffey syndrome
Klee Blattschadel
Klippel-Feil Sequence
Landau-Kleffner syndrome
Lange-Nielsen syndrome
Lanqer Giedion syndrome
Larsen syndrome
Laurin-Sandrow syndrome
Leber's Amaurosis
Legal blindness (bilateral visual acuity of 20/200 or worse corrected vision in better eye)
Leigh Disease
Lennox-Gastaut syndrome
Lenz Majewski syndrome
Lenz Microophthalmia syndrome
Levy-Hollister (LADD) syndrome
Lesch-Nyhan syndrome
Leukodystrophy
Lissencephaly
Lowe syndrome
Lowry-Maclean syndrome
Maffucci syndrome
Mannosidosis
Maple Syrup Urine Disease
Marden Walker syndrome
Marshall syndrome

Marshall-Smith syndrome
Maroteaux-Lamy syndrome (MPS VI)
Maternal PKU Effects
Megalencephaly
MELAS
Meningocele (cervical)
MERRF
Metachromatic Leukodystrophy
Metatropic Dysplasia
Methylmalonic Acidemia
Microcephaly
Microtia-Bilateral
Midas syndrome
Miller (postaxial acrofacial-Dysostosis) syndrome
Miller-Dieker syndrome
Mitochondrial Disorder
Moebius syndrome
Morquio syndrome (MPS IV)
Moya-Moya Disease
Mucolipidosis II, III
Multiple congenital anomalies(major organ birth defects)
Multiple Pterygium syndrome
Muscular Dystrophy
Myasthenia Gravis - Congenital
Myelocystocele
Myopathy - Congenital
Myotonic Dystrophy
Nager (Acrofacial Dysostosis) syndrome
Nance Horan syndrome
NARP
Neonatal Meningitis/Encephalitis
Neuronal Ceroid Lipofuscinoses
Neuronal Migration Disorder
Nonketotic Hyperglycinemia
Noonan syndrome
Ocular Albinism
Oculocerebrocutaneous syndrome
Oculo-Cutaneous Albinism
Optic Atrophy
Optic Nerve Hypoplasia

Oral-Facial-Digital syndrome Type I-VII
Osteogenesis Imperfecta Type III-IV
Osteopetrosis (Autosomal Recessive)
Oto-Palato-Digital Syndrome Type I-II
Pachygyria
Pallister Mosaic syndrome
Pallister-Hall syndrome
Pelizaeus-Merzbacher Disease
Pendred's syndrome
Periventricular Leukomalacia
Pervasive Developmental Disorder
Peters Anomaly
Phocomelia
Pierre Robin Sequence
Poland Sequence
Polymicrogyria
Popliteal Pterygium syndrome
Porencephaly
Prader-Willi syndrome
Progeria
Propionic Acidema
Proteus syndrome
Pyruvate carboxylase Deficiency
Pyruvate Dehydrogenase Deficiency
Radial Aplasia/Hypoplasia
Refsum Disease
Retinoblastoma
Retinoic Acid Embryopathy
Retinopathy of Prematurity Stages III, IV
Rett syndrome
Rickets
Rieger syndrome
Roberts SC Phocomelia
Robinow syndrome
Rubinstein-Taybi syndrome
Sanfilippo syndrome (MPS III)
Schinzel-Giedion syndrome
Schimmelpenning syndrome (Epidermal Nevus syndrome)
Schizencephaly
Schwartz-Jampel syndrome

Seckel syndrome
Septo-Optic Dysplasia
Shaken Baby syndrome
Short syndrome
Sialidosis
Simpson-Golabi-Behmel syndrome
Sly syndrome (MPS VII)
Smith-Fineman-Myers syndrome
Smith-Limitz-Opitz syndrome
Smith-Magenis syndrome
Sotos syndrome
Spina Bifida (Meningomyelocele)
Spinal Muscular Atrophy
Spondyloepiphyseal Dysplasia Congenita
Spondylometaphyseal Dysplasia
Stroke
Sturge-Weber syndrome
TAR (Thrombocytopenia-Absent Radii syndrome)
Thanatophoric Dysplasia
Tibial Aplasia (Hypoplasia)
Toriello-Carey syndrome
Townes-Brocks syndrome
Treacher-Collins syndrome
Trisomy 13
Trisomy 18
Tuberous Sclerosis
Urea Cycle Defect
Velocardiofacial syndrome (22q11.2 deletion)
Wildervanck syndrome
Walker-Warburg syndrome
Weaver syndrome
Wiedemann-Rautenstrauch syndrome
Williams syndrome
Winchester syndrome
Wolf Hirschhorn syndrome
Yunis-Varon syndrome
Zellweger syndrome